Whose health, whose care, whose say? Some comments on public involvement in new NHS commissioning arrangements

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Recent health policy in England has demanded greater involvement of patients and the public in the commissioning of health and social care services.   Public involvement is seen as a means of driving up service quality, reducing health inequalities and achieving value in commissioning decisions. This paper presents a summary and analysis of the forms that public involvement in commissioning are to take, along with empirical analysis from a qualitative study of service-user involvement. It is argued that the diversity of constituencies covered by the notion of 'public involvement', and the breadth of aims that public involvement is expected to achieve, require careful disaggregation. Public involvement in commissioning may encompass a variety of interest groups, whose inputs may include population needs assessment, evaluation of service quality, advocacy of the interests of a particular patient group or service, or a combination of all of these. Each of these roles may be legitimate, but there are significant tensions between them. The extent to which the structures for public involvement proposed recognize these possible tensions is arguably limited. Notably, new Local Involvement Networks (LINks), which will feed into commissioning decisions, are set as the arbiters of these different interests, a demanding role which will require considerable skill, tenacity and robustness if it is to be fulfilled effectively.

Introduction

In the last few years, a new direction has been evident in reforms to the National Health Service (NHS) in England. The initial focus of Labour governments since 1997 on reducing waiting times for hospital-based treatments has been displaced by a new emphasis on efforts to promote more flexible, 'personalized' healthcare provision, and make the NHS more 'patient centred'. The key mechanism for achieving such change is the quasi-market in the NHS, introduced in the 1990s, initially abolished under Labour, and subsequently reintroduced from 2001 onward. The existing split between purchasers and providers has been entrenched by measures to enable commissioners to purchase services from private- and not-for-profit-sector providers, and the introduction of patient choice of provider for elective surgery (Appleby & Dixon, 2004).

The shift is tangible in the rhetoric of recent policy documents, such as the health and social care white paper *Our Health, Our Care, Our Say* (Secretary of State for Health, 2006; hereafter '*OHOCOS*'). This contains various measures intended to further shift the balance of

power in the NHS away from acute hospitals and towards commissioners, including primary-care managers and general practitioners (GPs), and towards patients themselves. A key theme is the creation of new levers for commissioners of services, and new incentives for providers to respond to these, to drive "innovative" and "joined-up" services built around the needs of patients and clients in health and social care, rather than the interests of providers (*OHOCOS*, p.8). Within this, the role of public involvement in commissioning is given particular prominence, as a means of ensuring that providers respond to patients' preferences around quality, flexibility in provision and care closer to home.

Public involvement in the choices made by commissioners in the NHS quasi-market, and in priority setting more generally, is not unprecedented. In the United States, the well known Oregon experiment (Kitzhaber, 1993) represented an innovative (if ultimately ill-fated) effort to incorporate public values into health-care prioritization. In various developed-world countries, public-service commissioning regimes such as 'Best Value' have sought to incorporate public and community involvement of various kinds into procurement arrangements in health and other fields, to ensure that a collectively agreed notion of quality, as well as efficiency, is included in such decisions (Bovaird & Halachmi, 2001). In the developing world, community engagement in health-care planning is similarly deployed in assisting funding decisions in increasingly market-based systems (Meads *et al.*, 2007). In England, a specific precedent to the *OHOCOS* reforms is the introduction of public involvement in NHS and social care commissioning processes following the 1990 NHS and Community Care Act. This sought to ensure that 'local voices' (Department of Health [DH], 1992) were heard by health authority managers responsible for commissioning decisions, but for its critics was impeded by its consumerist and managerialist traits, which prioritized individual over collective interests and failed to empower those involved as citizens (Prior *et al.*, 1995; Milewa *et al.*, 1999).

Within *OHOCOS*, and associated documents giving the detail of commissioning plans, the role given to public participation incorporates both consumerist involvement premised on individual choice and collectivist involvement premised on participatory citizenship. These are both seen as a means of driving up quality, reducing inequity and improving cost-effectiveness (DH, 2006c, pp.5-10; DH, 2007, p.58), bringing together notions of collectivist 'voice' and consumerist 'choice' that have vied for prominence under successive British governments. As such, it may be seen as bridging the 'New Public Management' that informed the consumerist reforms of the early 1990s, and the 'community and local governance' discourse of communitarianism and recent social democracy (cf. Bovaird & Halachmi, 2001). Yet these aims around quality, equity and cost-effectiveness are evidently diverse, and to some extent in tension with one another (Harrison, 1998). Moreover, the public*s* that they require for their achievement are multiple and heterogeneous, and thus have potentially differential interests, as highlighted in much of the literature (e.g. Lomas, 1997; Harrison & Mort, 1998; Barnes *et al.*, 2003; Cowden & Singh, 2007; Martin, 2008). Whilst the need to consult wideranging publics is recognized in the policy documents, I argue in this paper that the potential tensions between these publics' views and policymakers' ambitions to involve 'the public', broadly conceived, in commissioning are underacknowledged. Furthermore, the proposed means of reconciling such conflicts in commissioning decision-making may be lacking.

In the next section, I consider the role put forward for public involvement in recent commissioning documents in more detail, drawing attention to the potential for conflicts between the voices of different publics that may make the goal of a unitary public input elusive. Following this, using empirical evidence from a recent study, I seek to illustrate how the input of one source that is cited in *OHOCOS* as a public to be drawn upon—service-user groups—may itself represent a multiplicity of perspectives and objectives, which are not easily reducible to the input of an identifiable, coherent constituency that policymakers seem to desire. Finally, I turn to the question of how public involvement in commissioning is to be put into practice, identifying

the challenges for the mechanisms proposed, especially those facing Local Involvement Networks (LINks)—the newly instituted form for patient and public involvement in England, which are given a special place in mediating between different publics' perspectives and feeding these into commissioning processes. How far, I ask, does this latest trend in public involvement overcome the tensions around consumerism and collectivism highlighted in the existing literature, and meet the challenges introduced by the effort to bring multiple constituencies into decision making?

Public involvement in commissioning: the policy

The ambition to improve the quality, equity and robustness of commissioning in *OHOCOS*, then, is explicitly based on using public involvement, among other levers, to increase the responsiveness of service providers:

> Commissioning is the process whereby public resources are used effectively to meet the needs of local people. The voices of local people will be vitally important in improving this process. Public involvement is part of our wider strategy to facilitate high-quality commissioning. (*OHOCOS*, p.161)

Thus public involvement is to inform every stage of the commissioning cycle, from assessing population needs, through prioritization and service design, to the management of performance and contracts with providers (DH, 2006c, p.6). Public involvement is cited as one of three drivers of service reform through commissioning, alongside commissioners' own expertise, and nationally determined standards, targets and regulation (DH, 2006b, p.12). Among these, the input of public involvement is considered the preferred driver, as it is seen to bring the decision-making process as close as possible to the ultimate users (and funders) of health and social care:

> We start with a preference for patient-driven approaches because that is what will drive greater responsiveness of care, putting choice and control in the hands of patients and users. But the balance of approach needs to be appropriate to the service in question. (DH, 2006b, pp.13-14)

In particular, the emphasis here is on direct choice of provider by individual patients (in consultation with GPs or social workers), as already implemented in relation to elective care provided in acute hospitals, and in individual budgets for users of social-care services.

It is acknowledged, however, that such direct choices of individual 'rational consumers' are not available in every area of health and social care provision, and consequently other means of ensuring public input into commissioning are required:

> *Patients*, through greater choice, will drive improvements in many services. For services where wide choice may not always be possible, the views of patients and *carers and families*, *groups of service users* and their *communities* should still substantially influence service provision. Other third sector organisations can often provide helpful insights into the needs of particular groups which may not be met adequately, or at all, by existing services. (DH, 2006c, p.4; emphasis in original)

The collective input of groups of service users, communities and third-sector organizations is thus to some extent seen as secondary to, or a substitute for, the direct choices made by individuals as consumers of health and social care. At the same time, though, there seems to be implicit acknowledgement in the passage above that these collective needs may not be effectively met through such consumerist involvement (Cowden & Singh, 2007). For example, if certain groups are unserved by existing provision, it follows that the input of *patients* will not give them adequate representation—hence the need for the advocacy of third-sector organizations. However, there are also potential conflicts between the interests of the "patients" and those of the "communities" alluded to above, which the policy documents do not address in suggesting transferability between individual choice and collective input as means of public involvement. These derive, for example, from the fact that the funders (taxpayers) and the recipients (patients

and users) of health and social care are overlapping but not identical groups (Lomas, 1997). Sometimes the differential interests of communities and patients are more overt, for example in relation to the location of mental health, drug rehabilitation or sexual health facilities (Parr, 1997).

The policy documents do also acknowledge that there are risks associated with unbridled consumerism as the primary means of public involvement. In particular, the need to consult widely, across the spectrums of society, is highlighted as crucial if equitability in service provision is to be secured:

> At the same time as giving people greater choice and control over the services they use, we also need to ensure that everyone in society has a voice that is heard. When people get involved and use their voice they can shape improvements in provision and contribute to greater fairness in service use. (*OHOCOS*, p.157)

A key conduit for amalgamating, consolidating and bringing forward these diverse views from various sections of society is to be the newly instituted forums for patient and public involvement in the NHS, LINks, which became operational from April 2008. These are charged with "gather[ing] information from a wide range of people and a wide range of sources […] such as PALS [Patient Advice and Liaison Services], complaints, the national survey, and through other means of engaging people such as dedicated websites, user groups and focus groups" so that they can act as "a means by which commissioners […] access the views of the local population" (DH, 2006a: 14). The role of LINks is considered in detail in the final section of the paper.

'Voice', then, is to complement 'choice' by providing a means of accessing the views of various 'communities of interest' across society. Alongside this, however, *OHOCOS* also presents a more consumerist dimension to the way 'voice' is to feed in to commissioning decisions. Public petitions about inadequacies in service provision that reach a certain absolute figure or proportion of local users or residents will trigger a review of commissioning decisions, and require a public response from primary care trusts (PCTs) (*OHOCOS*, pp.160-161). Policymakers seem conscious of the potential for such processes to be 'hijacked' by particular interest or lobby groups, and offer some guidance to commissioners in the detailed framework that followed *OHOCOS* on balancing competing interests in responding to such public petitions (DH, 2006c: 71-72).

Beyond the expectations placed on LINks, however, similar advice is not offered to managers and commissioners on how to balance competing interests in the less consumerist, more collectivist forms of public involvement that are to influence them. Given the above observations on the diversity of publics, and associated interests, to be taken into account, and the expectation that public involvement will secure equitability as well as quality in service provision, this is surprising. Rather, the notion of 'the public' tends to be constructed unproblematically in *OHOCOS*, with a collective perspective that democratically incorporates the views of diverse constituencies expected to emerge almost organically through the process of public involvement itself:

> We are clear that there has to be a means for the collective voice of people to be heard. The public should be able to take a view of health and social care in the round. (*OHOCOS*, p.159)

No means of adjudicating between competing voices is put forward: where a healthcare market might present one (albeit imperfect) means of accommodating differences of choice, there is no equivalent mechanism for dealing with potential differences of voice. Despite acknowledgement of the existence of competing interests among different groups in society, then, there seems to be an expectation—or hope—that public involvement in commissioning will arrive straightforwardly at "the collective voice of people," the public's view "in the round." In the next section, I present some analysis from recent research on one form of public involvement—service-user groups—seen in *OHOCOS* and associated documents as providing input into commissioning decisions. Here, I hope to illustrate the multifaceted interests and perspectives

that such groups present, which mean that their input cannot easily be objectified as articulating 'the needs of patients', or 'users' satisfaction with existing service provision', so further complicate the task of balancing this and other inputs.

User groups as a source of public involvement: the contributions

The data presented in this section derive from a study of user involvement in the introduction of a programme of seven pilot projects charged with implementing a new care pathway for patients with a suspected family history of cancer. These projects were cofunded by the DH and Macmillan Cancer Support, a third-sector organization which seeks to support innovative service provision in the field of cancer, and involve stakeholders, including clinicians, patients and carers, in the development, implementation and spread of such innovations. Consequently Macmillan placed a high priority on the inclusion of user groups (their members including as patients, carers and interested members of the public) in the development and management of the pilots themselves, and in its own strategic work around 'spreading' the lessons of the pilots across the NHS, engaging clinicians, managers and commissioners in the post-pilot mainstreaming of the new cancer-genetic care pathway.

My study of this user involvement process involved various qualitative methods. I conducted interviews with 12 user-group members (seven of whom were reinterviewed at the end of the programme), five staff responsible for supporting user involvement through Macmillan, and 28 staff from the pilots. Alongside this, I attended 33 meetings at which user involvement occurred over 30 months (17 pilot-level and 16 national-level meetings). Thirdly, I analysed pilot proposals, reports and evaluations, and Macmillan's own documents on user involvement. Here, I draw on the interviews with users and Macmillan representatives, and the observational work. Interviews lasted between 40 minutes and three-and-a-half hours, were digitally recorded and fully transcribed, and analysed with the assistance of NVivo 7. I read each transcript, set of notes and document several times, generating and coding themes iteratively according to issues identified in the literature and features of the data that became apparent more inductively. Findings were fed back to all three groups of participants in the research, as well as to the DH, as a means of triangulation and verification that the analytical frames applied to them seemed appropriate to respondents. The research was approved, as part of a wider evaluation of NHS genetics pilots, by the Trent Multi-centre Research Ethics Committee.

Macmillan and the DH were not specific about the form that user involvement in the programme and pilots should take. Consequently, user involvement served a variety of functions in different pilots, and often made several different contributions within single pilots. These covered, among other things, contributions to service development, evaluative feedback on provision, and active advocacy on behalf of the service (for example publicity or fundraising). Besides undertaking these varied activities in parallel to each other in any given site, user-group members' contributions also overlapped these different categories of involvement. So, for example, in one site user-group members facilitated focus groups of fellow patients to discuss questions of service quality and accessibility, feeding these back to service staff, and then participating actively in efforts to address the issues raised through service-development work. Elsewhere, user-group members were involved in designing patient-satisfaction questionnaires, drawing on their own direct experience of cancer-genetic service provision to inform the questions that would offer appropriate feedback for further improvements to the service.

The involvement of user groups, then, straddled the line between consultation and more direct participation in management decisions. Roles like this were negotiated through time between staff and user-group members, but for the latter, the various dimensions of the role were a logical and natural complement to one other:

> There's a lot out there to be tapped, and it's not just a case of, "She's a good fundraiser": it
> could be lots of different areas, because you're an individual, and you've got all sorts of

> different skills. I think that's a lot of it, besides the information, and besides not being told what you want [by services], I think there's a lot of skills out there they can tap. (User-group member)

A sense of affinity with other patients who experienced the long-term individual and familial consequences that arose from a cancer-genetic diagnosis fed into a desire to contribute actively to the development of these new services. Moreover, it also gave rise to an affinity with the *services themselves*, as pilots seeking to meet the needs of cancer-genetics patients, widely acknowledge as a previously underserved group (DH, 1998) (especially compared to the political and emotional clout of cancer in general). This was all the more the case in a competitive NHS funding environment in which, as Macmillan communicated to the user-group members, genetics was unlikely to be a high priority for commissioners. User-group members were thus passionate in their efforts to ensure that services were sustained and expanded, and potential patients catered for:

> We just need to get this service out to as many people as we can, keep it going, and spreading it out, 'cause when you get phone calls of people that are outside the area and you can't help them, it must be traumatizing. I can't imagine what that would be like, to be told, "We can offer this but it's not available to you, 'cause you're out of the area," I can't imagine what that's like when you're reaching out to get support. (User-group member)

In some sites, users were even directly involved in commissioning discussions with local PCTs, sitting alongside service staff as they made their case for extensions of funding or coverage. As a Macmillan employee commented at a forum for user-group members from across the pilots, "Have a user at your side, and the dynamics of these meetings are transformed."

The contributions of these user groups, then, were not easily categorized as offering the perspective of 'the public', user activism in relation to a specific disease area, or even advocacy work closely aligned with the interests of the service itself. Rather, the contributions cut across these categories in ways that seemed only natural to user-group members themselves. Furthermore, Macmillan itself saw the new emphasis on public involvement in commissioning as a crucial strategic opportunity. In an NHS otherwise dominated by centrally determined targets and standards, public involvement represented a "major card to play over these complexities":

> For new services, struggling to find new money from commissioners, the opportunity for healthcare professionals to work closely with service users to make the point to commissioners that here is a credible instrument that has been used to give a voice to the public—or patients and carers, however you describe them—is hugely valuable. […] The strong user view, well presented, articulate and reasonable, could well be the deal clincher, when all else is the same. (Macmillan service-development manager)

Rather than as a potentially distorting influence on commissioning decisions, such interested, partisan contributions were seen by the organization as a means of ensuring that issues relevant to this community of interest remained on the health agenda even as policy fads moved on. User-group members themselves were not mere pawns in this game, being used to legitimate Macmillan's political work (Harrison & Mort, 1998), but skilful and wilful actors who carved out intricate roles for themselves. One user-group member, for example, was scornful of her pilot's inadequate efforts at user involvement, while at the same time instrumental in orchestrating a letter-writing campaign to commissioners and newspapers in order to secure its future.

Arriving at "the collective voice of people": the practice

What is hopefully evident from the previous section is the variety of roles played simultaneously by one constituency identified in the policy documents discussed earlier on as a source of public involvement in commissioning decisions. The activities of the user-group members in my study cannot be seen to represent 'the public' or 'patients' or even, necessarily, 'users of these pilots'. This is not to suggest that the roles they play are illegitimate: merely distorting influences on the

'pure' cost-benefit-equity equations of commissioners—if indeed such pure trade-offs ever exist (Bate, Donaldson & Murtagh, 2007). However, what is clear is that even within this one, relatively homogeneous, 'community of interest', a diversity of perspectives and inputs is apparent, and these need to be distinguished and disentangled before even attempting to reconcile them with the views of other publics. The same sort of ambivalences and complexities are likely to be present in other constituencies' inputs into public involvement: for example, the notional 'local community' is likely to conceal a great deal of differentiation in terms of interest groups, needs and wishes. The association of some patient groups with pharmaceutical companies throw up still more complex sets of interests and allegiances (Novas, 2006).

As noted earlier on, while acknowledging their existence, policy documents on public involvement in commissioning do not give a great deal of detail to commissioners on how they are to identify and reconcile these competing 'voices' of publics. Previous initiatives have tended to leave it to NHS managers to adjudicate between the views of different publics, in the context of other pressures such as limited resources (Milewa *et al.*, 1999). With *OHOCOS* and its associated guidance, this responsibility has, rhetorically at least, been shifted somewhat. A heavy burden seems to be placed on LINks as a focal point for various forms of public involvement, and a conduit for the feeding of these into commissioning processes (DH, 2006d). Having gathered information on the public's needs and wants from a wide variety of groups and sources, LINks are then responsible for "analys[ing] the information and deciding what to pass on. They will identify and pass on trends and make recommendations to the organisations (commissioners, providers, OSCs [local government-based Overview and Scrutiny Committees] and regulators) responsible for delivering and scrutinising health and social care services" (DH, 2006a, p.14).

As has been remarked elsewhere (Martin, 2008), this interpretive, analytical, adjudicating function is a major responsibility to place on involved members of the public themselves, especially given wider ambiguities about the composition, representativeness and purpose of LINks (Hogg, 2007). 'Gold standards' in public involvement in decision-making, such as citizens' juries (Smith & Wales, 1999) and deliberative democracy (Abelson *et al.*, 2003), stress the importance of achieving broad-based participation in the process. Past experience with LINks' antecedents suggests that, on the contrary, their membership will be self-selected or appointed, and therefore lacking in "democratic legitimacy" (Baggott, 2005, p.546). As they start to adjudicate between the wishes of competing publics, LINks may well therefore find themselves susceptible to challenge around their legitimacy should their decisions upset those publics, especially the more powerful constituencies. That said, it is also important to note that every attempt at generating robust public involvement mechanisms is doomed to fall short of the deliberative-democratic ideal in some way: perfect representation of the full range of views and values across society, and the elimination of power from debates to achieve rational consensus, are ideals to be aspired to rather than fully realizable objectives. Furthermore, even the best-designed citizens' jury or deliberation exercise may be subject to managerialization, through processes of 'framing' and 'black boxing', or through selectiveness in the implementation of recommendations (e.g. Glasner & Dunkerley, 1999; Milewa *et al.*, 1999). By placing public involvement at the centre of the commissioning process, rather than as an adjunct external to decision making itself, it is possible that LINks may be more resilient to such managerialization, though only time will tell.

Proposals emphasise that each LINk "will have the ability to set its own agenda within the scope of its statutory functions, enabling local people to champion local issues" (DH, 2006a: 15). Whilst this discretion will undoubtedly be welcomed—and is also likely a necessity given the institutional arrangement of LINks as a focal point for diverse local public-involvement initiatives—it also, then, clearly holds dangers. As illustrated above, notions of 'local people' and 'local issues' conceal all sorts of heterogeneity—and competing interests. How far this discretion aids or impedes the ability of LINks to fulfil the complex balancing task they have been given

remains to be seen. For the British government's aspirations around quality, cost-effectiveness and (especially) equity, though, the success or failure of LINks and commissioners in reconciling these publics and their interests will be crucial.

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